The presenting symptoms associated with arachnoiditis and the experience of living with them in everyday life

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Abstract

A qualitative study was undertaken to explore and describe the symptoms associated with arachnoiditis and the experience of living them in everyday life. Using guide questions developed from the study's objectives, eleven people who believed they had arachnoiditis were interviewed to elicit descriptions of their symptoms and experiences. Research data revealed a broad range of symptoms, including severe pain in various areas of the back, headaches, sudden weaknesses leading to falls, fatigue, bowel and bladder problems, feelings of depression, suicidal feelings and plans for suicide, unexplained sweating, various sensations of pins and needles, electric shock, numbness, cramps, and spasms. Experiences identified as associated with living with these symptoms include mobility difficulties, problems in gaining understanding from others, the development of coping strategies, the search for relief from symptoms and enforced changes in lifestyle. The study revealed that nurses had played no recognised therapeutic role in participant's experiences. A change in focus is proposed, from a biomedical perspective of arachnoiditis as incurable and the symptoms, particularly the severe pain described by participants as intractable, to a Rogerian focus which emphasises the potentials in life. New possibilities for nurses to develop therapeutic practices, in particular, those focusing on pain management needs, are identified and linked to current opportunities for practice development.

Acknowlegements

With grateful thanks to the participants who shared so much,

to my wonderful husband, family and friends who endured,

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Chapter One: The aims and context of the research and an introduction to the participants

Introduction

In this chapter, the researcher introduces the study aims, outlines the background to the study and describes the researcher's initial involvement in the lives of those with arachnoiditis. A brief consideration is given to the choice of methodological and theoretical frameworks and the participants are introduced.

Study Aims

This qualitative descriptive study aims to:

- explore and describe the symptoms associated with arachnoiditis

- explore and describe the experience of life with those symptoms

Analysis of the data will provide, through the description of the symptoms and the understanding gained of the experience of living with those symptoms in daily life, information from which appropriate nursing practice options can be developed and/or further research undertaken that will enable those with arachnoiditis to live lives of greater comfort and opportunity.

Background to the research

In the latter part of 1995, a television programme (A shot in the back, 1995) and a number of newspaper articles (Doctors unsympathetic, 1995; Myodil group, 1995; Myodil group wants, 1995; Myodil sufferers may number, 1995; Myodil victims, 1995;

Myodil victims band, 1995; Myodil victims urged, 1995; Spinal dye used, 1995; Sufferers join, 1995; Wanganui Myodil sufferers, 1995), brought to public attention the existence of a pattern of symptoms which, for those featured, included a severe intractable pain centred in their spines that they had come to believe was related to a disease process known as arachnoiditis. Those interviewed believed that their symptoms had developed as a result of the introduction of a radiographic dye known as Myodil (see Appendix One) into their cerebro-spinal fluid for the purpose of myelographic x-ray examination, reaching this conclusion as a result of their own personal investigations into the medical literature.

Initial involvement of the researcher with those with arachnoiditis

The response to the ongoing publicity was such that those featured, particularly those in the television documentary, were unable to handle replies to all the correspondence and the telephone requests for help and information they received from people around the country. The Whanganui Disability Resources Centre (WDRC) was asked by one of the participants in the television documentary to assist in replying to these requests, and the researcher was asked by WDRC to coordinate a response to inquiries. This was a voluntary position, as no funding was available for a coordinator. However, WDRC was able to meet the costs of photocopying, telephone and postage as part of their mandate to provide support and information to those seeking it.

Establishing support links and information dispersal

By January of 1996, over 600 people had contacted WDRC seeking information because they felt they may also have arachnoiditis as described in the various forms of publicity. Accessing information to build an information pack proved difficult. Although there were a number of articles on Medline, it was not easy for the researcher, who at that time knew very little about the condition, to know which were likely to be the most helpful articles before ordering them. Eventually, some articles of a general nature were obtained and all those who contacted WDRC were sent an information pack

containing the names and contact phone numbers of people who had agreed to be local contacts, the titles and authors of relevant articles and a brief summary of the articles on arachnoiditis that the WDRC had accessed to that point, an outline of symptoms linked in those articles to arachnoiditis and a questionnaire allowing for expression of their feelings and needs concerning the situations that had developed for them since their symptoms appeared.

Emergence of areas of concern relating to symptom management

The questionnaire included in the WDRC information pack was not intended as a research tool, but simply as an in-house way of assessing the most urgent needs. Over 200 people responded to the questionnaire. Others wrote detailed letters. Responses were compiled but not statistically analysed (Whanganui Disability Resource Centre, 1996) and indicated that difficulties in getting a diagnosis, not being believed about the pain, not receiving adequate relief for the pain and not receiving help for difficulties they experienced in their day-to-day lives as a result of the pain, were the major areas of concern. Some respondents reported having been told by their doctor that the pain was 'all in their head' (ibid). Others reported being told by health professionals that they would 'just have to learn to live with it,' without support as to how to do so, or any explanation as to cause or likely future outcomes.

Individuals stated they had felt demeaned and helpless when told it was 'all in their head.' There were reports from relatives of people who felt loved ones had committed suicide as a result of such attitudes. In excess of twenty people who contacted WDRC indicated they were actively considering suicide, mostly because of the unremitting pain. Initial support for those people was provided throughout the country by field workers from the Multiple Sclerosis Society. There was a perception expressed by a number of respondents that specialists and the Accident Rehabilitation and Compensation Insurance Corporation of New Zealand (ACC) were in collusion, and were 'covering their backs' because they had ordered the tests knowing there was a linkage to the subsequent onset of the arachnoiditis. Individuals expressed their concerns about a perceived lack of choice in accessing specialists. After receiving

copies of their hospital and medical notes, a number of respondents stated their objections to the content of some of the entries in their medical histories, to letters written about them without their knowledge and to the lack of information they felt they had been given at many points during their contact with the health care system.

Formation of local and national support groups

Because so many people wanted support and understanding from others who shared their problems, efforts were made to establish self-help support groups. The willingness of individuals to act as contact people led to the formation of groups throughout the country. However, many initially active local groups ran into problems because of the ill-health and disabilities of the members. Attendance at meetings was erratic and problematic, since a number of people had difficulty sitting for any period of time, which also limited car travel and thus actually getting to meetings. There were disputes over the purpose of the groups. Some wished to concentrate on seeking compensation from pharmaceutical companies, while others wanted support and information. Since then, those seeking legal redress have formed a completely separate group and are working with two lawyers for that particular purpose.

WDRC does not have a mandate to fund support groups for those with disabilities and was pleased when a local support group was formed. Members of that local support group also became the founding executive of the national body, the Arachnoiditis Support and Monitoring Society (ASAMS). ASAMS faced a huge task and the provision of information and support for members initially taxed the resources of the newly formed national group.

Since that time, ASAMS has continued to evolve. Links have been made with other arachnoiditis support groups overseas, members coincidentally discovering the distractive therapeutic value of computers as they became computer literate. ASAMS has its own web site. Members have scoured the Internet and joined chat pages for those with arachnoiditis. Information from Medline abstracts has led to the acquisition of

journal articles on a wide range of aspects concerning arachnoiditis, from aetiology to treatment, including research on specific dyes and their side effects. Copies of many of these journal articles have been accessed through libraries, the Ministry of Health and other national groups, especially the British Arachnoiditis Trust. Video's from Dr Burton of the Minnesota Back Pain Facility, an acknowledged and widely quoted expert on arachnoiditis, were obtained. Some ASAMS members are now very knowledgeable about arachnoiditis related information.

ASAMS has developed a collective awareness of just how poorly served some of their members felt they had been in the area of pain management. What had been isolated individual experiences have been shared. ASAMS also reported an ongoing perception among members who receive payment from ACC that ACC appointed doctors they were required to see to maintain their payments have been particularly unsympathetic and unhelpful.

Recently, ASAMS held a regional get-together for members in the lower North Island, at which the researcher was an invited guest. This meeting allowed members to meet and discuss many of the above issues and to clarify their goals for the National organisation. They also met their new patron, a South African doctor who has recently moved to New Zealand. Some of those who attended had never met anyone with their particular difficulties before and had felt extremely alone, so the meeting proved very fruitful in terms of personal support networks.

Rationale for selection of arachnoiditis as a topic requiring nursing research.

The idea that the researcher might undertake her Master's thesis research on some aspect of arachnoiditis was suggested to her by the executive of ASAMS. This request reflected the concern of members, who had expressed disquiet that so few health professionals appeared to be knowledgeable about the condition, and seemed unable to validate members' experiences by saying what symptoms people 'should have.' There was concern that the kind of support needed to live with their pain, particularly their

back pain, was not recognised as being different from that associated with acute pain or chronic pain of other causation. Members had reported feeling that the personal devastation they had experienced on finally getting a diagnosis, only to be told their condition was an untreatable one they would have to learn to live with, had not been recognised and appropriate support had not been offered.

The problems outlined above indicated a number of systemic issues, not all of which related directly to nursing. However, there is a linkage with a number of issues discussed in nursing literature over the years. These include nurse-patient advocacy (Johnstone, 1989), the rights of individuals to informed consent provided under the Code of Health and Disability Services Consumers' Rights Regulations (1996) and the leading role nurses have had in developing new approaches to pain management programmes for acute pain and cancer associated pain. (McCaffery & Beebe, 1989).

In particular, realisation of the scarcity of readily accessible, comprehensive, recent information on arachnoiditis for nurses emerged. A search of the international literature on Medline and Cinahl, the literature available from ASAMS and sources referenced in other articles, did not find any published, researched nursing studies on arachnoiditis. Study of nursing texts available to the researcher through university and hospital libraries did not discover any nursing information explicitly about arachnoiditis. Nor was knowledge of the symptoms much more readily accessible in the medical literature and crossover links between the arachnoiditis literature and the literature on central pain syndromes were not found. These gaps confirmed the need for an exploratory descriptive nursing research study to provide a base on which to build further research. The choice of this topic was thus spurred by the request of those who experience the symptoms and by 'curiosity and compassion' (Rogers, 1970) on the part of the researcher.

Choice of a Rogerian Nursing Framework

This study, in seeking to explore and describe the symptoms and experiences of people who believe themselves to have arachnoiditis, requires a theoretical perspective that can

encompass analysis of the descriptions revealed at interview within a nursing framework. People who believe themselves to have arachnoiditis are usually community-based, not hospitalised, and a framework that encompasses the open systems within which they live, such as family and community systems, enables the nurse to work from the person's perspective to maximise potentials within their individual life circumstances. Such a framework is provided by the science of unitary human beings (Rogers, 1970, 1980, 1986, 1988, 1990, 1993, 1994), which gives nursing an organised, abstract system encompassing people and their environments (Rogers, 1986).

Wider applications of the study results.

It was felt by members of ASAMS that the descriptions arising from an exploratory descriptive study could be used both as an educative tool for themselves, their families and friends and for health professionals who are eager to help but have little available information on which to base their care. The findings of a descriptive exploration framed within the science of unitary human beings is seen as being able to meet this goal and to provide professional nursing knowledge that is both independent of, and yet complementary to, medical diagnosis and treatment. This will hopefully open the way for innovative, mutual care options for an erstwhile ignored problem that seems to be largely considered incurable and intractable.

The participants

Of the eleven participants, eight were men and three were women, ranging in age from their early thirties to early seventies. They came from a wide range of work backgrounds. All the participants, except one, are in an ongoing relationship with a partner. All the participants have children from either their current relationship or previous ones and all but three of the participants currently have children living at home. Two participants are in part-time paid employment, one is self-employed, one is retired, and the others are involved in various voluntary organisations. All are members

of ASAMS and, at the time of entry to the study, all believed they had arachnoiditis. The following historical data was revealed at interview. Participants were asked if they had a confirmed diagnosis, whether it had changed over time, how long they had had symptoms and whether those symptoms had changed over time.

Brief introduction to participant's histories.

Participant's recounting of the events they relate to the development of their back problems, including arachnoiditis, did not always clearly fix events to dates. For some participants the sequence in which events happened was given, but only vague dates. Others, who had accessed their old hospital notes, were able to be more specific with dates, which have been included in the data. They related the following histories at interviews.

Greg

Greg officially injured his back at work by twisting as he stood up but he inclines to the view that he initially injured it during a rugby match during his teenage years. Since that time he has had several exacerbations of low back pain, for which he was treated with bedrest. He had a myelogram in 1983. He has not had any surgery. Most recently, he has been told that his lower lumbar discs have degenerated and that this is affecting the exiting nerves leading to his legs.

Jack

Jack had a rugby accident in 1986 that compacted his neck down into his shoulders and compressed the vertebrae. Initially told he was a *"nutter,"* he was eventually found to have a cervical bone splinter, which was removed during surgery in 1987. Surgery relieved the headaches, dizzy spells and tendency to collapse and fall and he returned to full time work. In 1988 he suffered another accident at work when a heavy piece of machinery fell on him, causing lumbar back pain. His symptoms were initially thought to be *"in his mind"* but were eventually diagnosed as two collapsed vertebrae. After a

spinal fusion in 1989, he was told he has large areas of scar tissue at the lumbar injury/surgery site. Jack has had two myelograms, one of which required seven attempts to insert the needle. He does not know which radiological contrast agents were used for his tests. Jack has not asked his doctor about arachnoiditis, despite deterioration in his mobility, for fear of being disbelieved again.

Jane

Jane had an accident in 1986, in which she slipped over. Despite the pain, she continued heavy lifting in her work at the time. Eventually, the pain became so severe she could not straighten up properly. She gradually decreased her hours of work from full time down to none because the pain down her leg was so severe. Jane now feels she was *"a fool"* and should have *"given in"* earlier. She attended physiotherapy and a rehabilitation programme and then had a myelogram in which the radiographic contrast Iopimiro (Appendix One) was used. This showed a prolapsed disc. Two weeks later, she had a laminectomy. The pain was relieved for three months after surgery but sciatic pain returned as her mobility increased. There has since been an increase in *"deferred"* [sic] pain and the onset of headaches and weakness in the legs, leading to a clinical diagnosis of arachnoiditis by her operating surgeon and her general practitioner. She has never had a Magnetic Resonance Imaging (MRI) scan because ACC does not fund a *"peace of mind"* diagnosis. Jane also has a diagnosis of fibromyalgia.

Jim

Jim's problems began in 1980 when he suddenly found himself unable to get out of bed one morning. He could not relate this to any particular movement or trauma. He was given a series of hydrocortisone injections in the spine, and a laminectomy for *"jammed nerves"* in 1981. Five weeks after his laminectomy, he was in a car accident. No x-rays were taken at this time because he said he felt all right. Between 1981 and 1986, he had two myelograms for investigation of back pain, in which the radiological contrasts used were Pantopaque (Myodil) for the first and metrizamide for the second. In 1986, Jim had a bone graft to his spine. During this surgery they *"nearly lost"* him because of excessive bleeding and difficulty *"getting in"* to the site because of large amounts of

scar tissue. His symptoms were much worse after that surgery and he was unable to walk far because of a tendency to collapse. In 1989 he had further bone grafts and a metal implant in the lumbar spine area, which was replaced in 1993 with a titanium implant. No mention was made by any of the operating surgeons of the possibility of arachnoiditis. He subsequently discovered that an MRI he had had in 1989 in the United Kingdom had confirmed a diagnosis of arachnoiditis. Since 1986, he has also been told he has arthritis, fibromyalgia and raised cholesterol and blood pressure. He was also admitted to a psychiatric ward at one period because his doctor at the time attributed his symptoms to depression. At the time of interview he was being investigated for either *"tuberculosis"* or *"a blood clot on the lungs"* for chest symptoms occurring after a long air flight overseas.

Mary

Mary was left holding the full weight of a heavy person when a hoist broke, leaving her with a sudden pain, like a *"broken arm"*, in a very localised area of her back. She received epidural steroids for pain management, after which she had sciatica down one leg. In 1989, she had surgery, with improvement for about six weeks, followed by loss of function and numbness in her legs. The *"broken"* sensation continued. A second series of epidural steroids was followed by a sensation of burning. Surgery in 1990 showed webbing and scarring that she, as a result of her reading on the subject, considers indicative of arachnoiditis but she has not had this clinically or radiologically confirmed. Although her current diagnosis is nothing more definitive than *"chronic back pain,"* she reports being told she will become paraplegic.

Mick

Mick, prior to 1983, had a truck accident, after which he immediately went back to his work, which involved heavy lifting, because he *"felt all right."* Next morning, his back *"started to play up."* In 1983, he was injured when he jumped off the back of a truck and *"squashed the vertebrae."* He had a period of traction in hospital and bedrest for three months at home while waiting for a Computed Tomography (CT) scan, eventually opting for a radiculogram in 1984 because there was less of a waiting list. In September

of 1984, he had a laminectomy for a large lumbar extruded disc fragment. This improved his walking but left continued pain in his back. He was given psychotherapy, which he considered inappropriate. His current diagnoses are tinnitus, sugar diabetes, and old back injury.

Paul

Paul has had no injury that he recalls. In 1987, he had a laminectomy L2-5 for *"a lot of back pain"* over the previous two years that his G.P., physiotherapist, chiropractor and acupuncturist had been unable to relieve. His operating surgeon said a disc had clamped off his spinal cord and without surgery he would be in a wheelchair in a few years. He had a myelogram prior to the surgery. Surgery went well and he healed *"beautifully."* In 1993, he visited his doctor because of deteriorating mobility. An MRI report stated that *"the appearance is highly suggestive of post-operative lumbar arachnoiditis."* In 1997, he had a worsening of his mobility, accompanied by a tendency to fall and he now uses a walking frame. He has been advised against further surgery.

Rose

Rose's original injury was in 1987, when she had an accident while carrying a heavy wood basket. This was diagnosed as a prolapsed disc, with 15% disability. Her first intervention was a steroid injection of Depo Medrol in 1989, after which there was a permanent sensation of cramp in one leg, with increased mobility problems. A subsequent CT scan showed the nerve root to be grossly enlarged and she had surgery for nerve root decompression. A second series of steroid injections in 1994 was followed by the development of an arachnoid cyst. Rose has had a diagnosis of arachnoiditis from some doctors, but not from others. She also has a diagnosis of osteoarthritis in both knees.

Terry

In 1973, Terry had an operation for hiatus hernia, in which a lower rib was removed to gain access to the operation site. After this surgery, he had a major reaction to the iodine

skin paint used and developed a raw, weeping rash. In 1978, he had *"quite a big fall"* at work, which split his sternum open when he landed on his back on the breathing apparatus he was wearing. He had another fall in 1987, in which his feet were knocked straight out from under him and he landed on his *"bum and compacted my coccyx."* Two months later, after a briefly successful epidural steroid injection for pain relief, he was invalided out of his job.

Tom

Tom has had five surgeries since 1979, when he deflected a piece of heavy equipment that fell off a crane on to him. He was initially told by one specialist that his symptoms were due to spondylolisthesis and by another that he would come *"right"* in twelve months. In 1982, after no improvement, he had a laminectomy for *"compressed L3, 4 & 5,"* followed eight months later by a second laminectomy. Tom is unclear about the exact dates but in about 1984 he had a *"double sided fusion."* This fusion was broken during an x-ray in 1985, followed by a *"triple fusion"* which left him with loss of the use of his right leg, a *"drop foot"* and some numb areas. Further surgery in about 1987 has been followed by increased problems with his mobility. In 1993 he was given a diagnosis of arachnoiditis, which was shortly afterwards rescinded in favour of psychological explanations. In 1996, the conclusion from an *"expert in the field"* was that he is totally paralysed from the thoracic region down. In 1997, one month before interview, he was given a confirmed diagnosis of adhesive arachnoiditis. Tom's health has continued to worsen and he was too unwell for a second interview to take place.

Will

Thirteen years ago Will fell backward from a height at work, landing on his back on a pile of metal rubbish. An x-ray at that time showed no damage but his back continued to be sore afterwards. He had physiotherapy and acupuncture without relief and then had a myelogram with metrizamide dye after which *"chemical meningitis"* developed. He was hospitalised for five days. He has subsequently developed a number of so far unexplained symptoms and currently has no diagnosis to explain those in his back. He has had no surgery.